



June 30, 2020

Re: Speaking Up For Us Testimony to Appropriations and Financial Affairs Committee regarding CARES Act Funding

Dear Members of the Appropriations and Financial Affairs Committee,

My name is Monique Stairs and I am the Interim Executive Director of Speaking Up For Us (SUFU). I want to thank you for this opportunity to testify today on behalf of self-advocates across Maine.

SUFU is Maine's Self-Advocacy Network for people living with Intellectual and Developmental Disabilities (I/DD). Self-Advocacy is part of the civil rights movement for people living with I/DD to advocate and voice their experiences and opinions on issues that are important to them. Self-Advocates have been organized and advocating for the rights of people living with I/DD in Maine since 1993.

These last several months have been an unprecedented time in our state for all Mainers, but the COVID-19 pandemic has especially affected people who live with I/DD. In the middle of March, SUFU immediately shifted our business model to provide a response and support system of self-advocates across Maine. We began offering twice weekly phone calls over video conferencing as a means to hear the concerns and experiences among our members. We also began participating in national self-advocacy calls with people with I/DD across the country and learning about how COVID-19 is affecting Americans everywhere.

During this pandemic, we have participated in a lot of advocacy and identified several systemic issues which include:

- Increased healthcare disparities among people living with I/DD, which included concerns that were addressed by the Office of Civil Rights regarding both access to respirators if needed and the rights to bring a support person to assist with communication and support needs during any medical treatment regardless of hospital visitation policies. Press releases regarding these two issues can be found here: <https://www.hhs.gov/civil-rights/newsroom/index.html>
- Congregate group home settings have increasingly become hotspots for COVID-19 outbreaks. Several self-advocates who are active in SUFU have been exposed and tested positive. Self-advocates have shared concerns of being kept inside their group homes and forced to move to quarantine homes if they choose to go out in the community. Meanwhile, their support staff are coming and going and bringing the virus back. People with disabilities are being denied access to the community. There are also growing concerns or rights violations, and lack of PPE available for advocates to investigate.

- Many facility-based day programs closed completely in response to COVID-19 leaving many people living with I/DD with no services. This caused a gap of support for many of our SUFU members receive the communication and support necessary daily. In many cases, SUFU staff provided the needed support over Zoom. Some providers were able to adapt and begin using technology to provide supports, while others remained closed and recently began reopening. The Office of Aging and Disability Services (OADS) did work to issue guidelines for re-opening facility-based day programs, though there are still concerns over facility based congregate settings for community supports. People with I/DD have had pressure to return to day-programs even though the risks to their health may be greater than the need for parents, shared living providers or others to get back to “normalcy.” COVID-19 has certainly been an opportunity to identify many systemic issues within the current service model of which can be improved. Self-advocates had mixed decisions about returning to day-program and have been utilizing the COVID-19 Risk Benefit Guide that was issued by OADS.
- A lack of disability representation has also been a major concern for self-advocates regarding COVID-19 decision making. This has included the representation on the re-opening task force and has been especially concerning considering the number of known cases in group homes in Maine. Self-advocates are also concerned about the lack of information regarding what they can do to protect themselves from exposure from their support staff and having access to adequate PPE.
- Access to technology has been an issue for self-advocates to remain connected. More community support programs could have continued to provide tele-health services to people if more people had access to devices, internet connection, and training on how to use programs like Zoom and Skype. SUFU has worked hard to assist self-advocates who attend our regular chapter meetings around the state to stay connected. The Maine Developmental Disabilities Council purchased and distributed 148 tablets to people with disabilities and this has helped some SUFU members directly. Through the emergency K-Waiver that OADS applied for, money was also made available for technology, however when self-advocates asked about this many of their case managers were unaware of this option. Communication about how to obtain and use technology is needed here in Maine.

Most recently, one of SUFU’s strongest self-advocate leaders was diagnosed with COVID-19 because of exposure through support staff. This self-advocate has felt backlash for speaking up about practices happening in the home that are against the CDC guidelines. If this is happening in this home, it is likely happening in other homes.

SUFU would ask the legislature to consider the following areas when making decisions regarding COVID-19.

- When making decisions, seek further input directly from people living with disabilities and/or their family members in future decision making regarding COVID-19.
- SUFU also strongly feels that access to proper PPE for disability rights advocates would be beneficial for the protection of people living in congregate settings and attending facility-based day programs. People living with disabilities need support right now more than ever.

- In addition, self-advocates themselves need access to proper PPE for their own protection and easy access to testing if a staff member or other person with a disability (who they may have come into direct or indirect contact with) receives a positive diagnosis of COVID-19.
- There is a continued need to address the Section 21/29/18/20 HCBS services wait lists. The system was already in crisis before COVID-19 and is continuing to grow during this pandemic. Many families are continuing to wait for an offer on services. Dale and Lisa Keegan of Fort Fairfield, who testified on the wait list bill back in February are still waiting to receive services for their daughter Darby. The wait lists must be addressed as soon as the legislature comes back into session.
- Finally, there are many hardworking DSP's who have adjusted their schedules and family lives to respond to people during the COVID-19 pandemic. They have placed their own health and that of their families at risk by continuing to work. This group of workers in Maine are essential and relied on by people with disabilities for their daily support and the legislature should consider approval of hazard pay.

Historical treatment of people with disabilities shows how easy it is to devalue people based upon their disability. Marco, a self-advocate from Brewer Maine shares, "No one should be made to feel like they are expendable in a situation like this. Historically, people with disabilities have been left to fend for themselves in a time of emergency. People with disabilities should be more of a priority, and less of an option to society."

In closing, I will leave you with some words from Hope, a self-advocate from Fort Fairfield who stated, "We are more than what other people can ever see of us." SUFU will continue to bring forward the rights of people living with disabilities. I thank you for your time and the opportunity to bring up concerns of people living with disabilities.

Monique Stairs, Interim Executive Director, Speaking Up For Us

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